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**The experiences of British South Asian carers caring for a child with developmental
disabilities in the UK**

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&

John Rose**

Purpose: This study explores the role of culture in shaping the caregiving experiences of British South Asian families caring for a child with developmental disabilities in the UK. In particular it explores how the coexistence of two distinct cultures (British/South Asian) impacts upon these caregiving experiences.

Method: A qualitative design using in-depth interviews and interpretative phenomenological analysis was used with seven parents, identifying as British South Asian, who had been born in the UK or had moved to the UK as young people.

Findings: Three master themes emerged: Living with loss, uncertainty and overwhelming responsibility; Learning about disability and facing stigma; and Having to cope.

Research implications: Using a relatively homogenous sample of carers this study provides an insight into how exposure to two different cultures shapes the understanding and adaptations of British South Asian carers in the UK.

Social implications: Issues in the acculturation of these parents emerge which demonstrate the tensions they face in relating to both South Asian and Western cultural influences. The study makes recommendations for how services can work with such families in order to help them make sense of their children's disability, access culturally appropriate support and cope with the numerous demands of being a caregiver.

Originality/Value: This paper contributes to a growing literature on the experience of South Asian parents who care for children with intellectual disabilities. It has important messages for workers who support these individuals in how to provide the most effective support.

Keywords: culture, caregivers, South Asian, learning disabilities, intellectual disabilities

Introduction

The term 'South Asian' is a complex one and, in the UK, usually refers to people who originate from India, Pakistan, Bangladesh and Kashmir (British Sociological Association, 2005). South Asians are a diverse group made up of a number of sub-groups such as Indian-Punjabi, Indian-Gujarati, Pakistani-Mirpuri and many more. Groups have their own languages, religious practices and migration histories. Within each group, there is often great variation in terms of education, financial status and social status. Individual positions on cultural and ethnic identity tend to be complex and may be influenced by multiple practices. This heterogeneity of 'South Asians' is likely to impact on the experiences of caring for a child with intellectual/developmental disabilities.

There is little research exploring how British South Asians in the UK make sense of and handle their relationship with two cultures. A small number of studies have explored identity formation amongst South Asians living in Britain and found differences in acculturation attitudes amongst different ethnic groups. For example, Indians (Punjabi Sikh and Gujarati Hindu) are thought to favour integration strategies thus demonstrating bicultural identities in comparison to Pakistani Muslims who are thought to favour segregation strategies and a preference for their culture of heritage (Azmi et al. 1997; Ghuman, 2003; Robinson, 2009). Studies also suggest that making sense of everyday life and trying to form a sense of self when exposed to two different cultural lenses can lead to negative socio-psychological consequences or acculturative stress (Berry, 2005).

Little is known about how exposure to two different cultures in British South Asian communities influences caregiving experiences. Acculturation is the process of cultural and

psychological change which results when two cultures meet (Berry, 1997). For example, McCallion et al. (1997) used qualitative focus groups with African, Chinese, Haitian, Hispanic/Latino and Korean Americans to explore how acculturation impacts upon the experiences of people caring for a person with developmental disabilities. They found that families demonstrating higher levels of integration with majority cultures did not experience language barriers, had better uptake and relationships with services, and were less likely to subscribe to religious or cultural explanations of disability. Little is known about the impact of acculturation on South Asian groups caring for people with disabilities in the UK.

Aims of the current study

The current study aimed to explore how British South Asian parents make sense of caregiving in the context of two different cultures. Recent policy drivers have recognised the need to develop culturally sensitive support services for ethnic minority groups. Documents such as *Learning Difficulties and Ethnicity: A Framework for Action* (Department of Health 2004), *Valuing People Now* (Department of Health 2009) and *Learning Difficulties and Ethnicity: Updating a Framework for Action* (2012) all make recommendations for improving services for South Asian families.

It was anticipated that using a qualitative method such as Interpretative Phenomenological Analysis (IPA) would identify how participating South Asian parents living in the UK make sense of and experience their caring roles, and examine how culture may shape these experiences. It was hoped that findings would contribute to theoretical models of help-seeking and the development of more culturally accessible and acceptable services.

Method

Context

The research was conducted within two areas, one a small city and the other an urban borough, both within the English West Midlands. A National Health Service (NHS) Intellectual Disability Team, and carers' support group run by a charity helped support the recruitment of participants. The 2011 census (Office of National Statistics) revealed that 18.8 per cent of the city's population and 6.0 per cent of the borough's population were of an 'Asian' ethnic origin, made up primarily of Sikhs and Muslims.

Ethics

NHS Ethical approval was obtained. Written consent was obtained from all participants prior to beginning the interviews. All interview data remained anonymous, using pseudonyms to preserve participants' identities.

Participants

Potential participants were family caregivers of South Asian origin. First contact with the parents was through service providers who then referred the individuals to a researcher. Seven parents were interviewed, including 5 mothers and 2 fathers, all from separate families. This is in keeping with the recommended number of participants required for an IPA study of 6-8 (Reid et al. 2005). Participant details are shown in Table 1. Participants were aged between 27 and 42 years old. Three were born in England, three in Pakistan and one in India. All participants described themselves as British South Asian. The parents who were born in Pakistan and India had lived in the UK for 10-20 years. Parents identified themselves as either

Muslim or Sikh. All parents were bilingual or trilingual and were married to a partner born in England, Pakistan or India.

All the parents involved in the study were full time caregivers to children with intellectual/developmental disabilities born in the UK. Five parents reported having a child with intellectual disabilities (either moderate or severe), two a child with autism. Four of the children were girls and three were boys. Children were aged between 7 and 14 years old, ensuring relative homogeneity of the services available to parents and increasing the likelihood of shared caregiving experiences.

Insert Table 1 about here

Interviews

The interviews lasted up to an hour and a half. Four interviews were conducted in the parents' homes, two at the carers group meeting venue and one at the child learning disability team's meeting room. All interviews were conducted in English. In some cases participants referred to specific words or phrases in either Punjabi or Urdu which were translated by the researcher who is able to speak and understand both languages.

The interview schedule was influenced by the literature as well as the findings from a previous study (Heer *et al.* 2012) which highlighted the role of culture in shaping how disabilities are understood and interpreted by South Asian communities. Insights from this study suggested a mismatch between South Asian constructions of disability in comparison to

more Western and medical constructions. The schedule was carefully considered so as to allow respondents maximum flexibility to develop their own thoughts and descriptions, with minimal input from the researcher. The interview questions explored four main areas:

1. Background demographic information.
2. Recognition of the developmental delays associated with the disability.
3. Impact of the disability.
4. Belief systems.

All interviews were digitally recorded and subsequently transcribed verbatim.

Analysis

All transcripts were individually analysed using an interpretative phenomenological analysis (IPA) framework (Smith, Flowers and Larkin 2009). IPA aims to explore the meanings that particular experiences evoke for individuals in order to understand how those individuals make sense of their world. The initial analysis was undertaken by the first author and involved reading each individual transcript whilst making preliminary notes. This was followed by a more detailed reading in which the meaning of the text was examined and statements of similar meaning were grouped into clusters for each individual. These clusters thus formed sub-themes for participants. These sub-themes were then grouped in terms of similar meaning across participants in order to create “master” themes that reflected the whole group.

To ensure validity of the resulting themes, triangulation was achieved in two ways. Firstly, an independent researcher reviewed two transcripts which had been annotated by the first author.

Although similar or different themes were noted, there was overall agreement with the emergent themes created by the researchers. Secondly, the initial master and sub-themes were developed through a process of discussion and negotiation between the three authors which provided a means of cross checking.

Results

Following analysis of the transcripts, three master themes emerged and are presented with their sub themes in Table 2. This table also demonstrates how many participants are represented within each theme.

Insert Table 2 about here

Master theme 1: Living with loss, uncertainty and overwhelming responsibility

This master theme highlights the challenges associated with caring for a child with disabilities, including both the practical hands-on and the emotional aspects. It is concerned with how parents' and families' lives are affected by the child's impairments, and how these impairments are accommodated. The master theme is made up of four sub-themes.

An uncertain future

Parents talked about uncertainty arising from not being able to predict how the future might turn out and consequently living on a “*wait and see*” basis:

Khalida: “It’s so different in every child, I can’t compare it to anyone, so I keep reading to see if I can get some sort of a hint, how it’ll be like as he’s getting older, but because it’s so different in everyone, it’s just like wait and see.”

Stress and anxiety were associated with this uncertainty because the parents did not know what to expect in the future.

Kabir: “She’s getting bigger and bigger, sometimes I just keep thinking ‘what is going to happen to her?’ I lay awake at night thinking, it’s very difficult.”

Concurrent losses

The parents also reported grief over losses, both personally, and as a family. For example, in the extract below, Nazia describes her husband’s reaction to finding out about his son’s disabilities, including grief and disappointment over the loss of the son he had expected:

Nazia: “He (dad) was crying, he does love him, but he’s like disappointed about what happened with his little boy.”

Some mothers talked about having to make personal sacrifices in order to accommodate their new caregiving duties which often resulted in a loss of their own lives. For example, in the extract below, Sanjit describes having to put her career aspirations on hold in order to meet the needs of her daughter:

Sanjit: “I still wanted to pursue the nursery nursing and I thought ‘right college give me a crèche so I’ll try that option’...and for the whole time I’d leave her she’d cry. Completely non stop crying till the minute I got back, I just couldn’t even you know start the course, let alone finish it.”

Fears about vulnerability of child

Parents also described concerns about their children's safety and perceptions that their children were either a danger to themselves or in danger of being taken advantage of by others.

Khalida: "It seems like he would easily be taken advantage of, he can easily get misled, cos he doesn't understand what's happening around him."

Concerns about safety and vulnerability appeared to be linked to the unpredictable, dangerous and sometimes socially inappropriate nature of their children's behaviour, both at home and in public, which exposed them to various threats:

Nazia: "You can't leave him alone for five minutes, he's all over the place, he's just basically dangerous to himself cos he doesn't know exactly what he's doing."

All the mothers associated the root cause of their children's vulnerability with their lack of understanding about safety and risk. Through comparisons to other children of similar age, the mothers pointed out that, although their children physically looked their age, they behaved younger:

Kulbir: "She's behind, she's fourteen but she acts like she's four or five years old. That's the problem."

Consequently, caregiving duties were consumed with the constant supervision of their children in order to minimise their exposure to dangerous situations.

Managing multiple responsibilities

Mothers, in particular, described the challenges associated with the non-stop demands of caregiving. For some parents the intense and continuous nature of caregiving was likened to

the demands of a “*twenty four hour job*”. The mothers also reported having additional domestic responsibilities on top of their caregiving duties:

Khalida: “While they’re at school I’ve gotta rush and do all the things that I can before they get back. It’s like all my shopping and paying my bills and everything. I’ve just gotta do while I can, so that once they’ve come home I can just sit at home with them.”

Master theme 2: Learning about disability and facing stigma

This theme describes the parents’ initial recognition of their children’s delays and their responses of shock and confusion to the diagnosis across five sub-themes. Additionally, the theme highlights the stigmatisation associated with the diagnosis and awareness that their child was not a typical child.

“Everything was delayed”

This sub-theme retraces the parents’ initial recognition that the development of their child was not proceeding as they had expected. One mother described it as “*everything developed late*”, indicating delays in reaching normal development milestones. The most noted concerns were delays in speech, language and social behaviour. Several of the parents described their children as being very unresponsive.

Khalida: “At two, he wasn’t crawling, no babbling, he wasn’t doing nothing, wherever you left him, he’d stay there. He wasn’t interacting with

anyone, even if he had a wet nappy no crying nothing, nothing bothered him.”

Struggling to understand the diagnosis

For other parents, for whom this was their first child, recognition of the delays proved harder as they lacked experience and knowledge of what was considered to be ‘typical’ child development. These parents felt that having an older child may have provided a comparison, and earlier validation of their concerns:

Adeela: “When she was younger I couldn’t tell because she was my first child, I didn’t understand, I didn’t realise it is different from a normal child, to having a child with it.”

They also described feeling shocked when first hearing of their children’s diagnosis. For one mother, not being able to understand the diagnosis and not being given thorough explanations, led to an underestimation of the severity of the disability, as if it were something that would pass over time:

Khalida: “I didn’t know what it was, I was just sitting there thinking ‘I’ve heard of that’ but I didn’t know, I was like ‘ maybe he’s gonna be a bit slower, he’s just gonna have a bit of a learning difficulty and he’ll grow out of them’, they didn’t explain to me what it was.”

“They just don’t understand it”

Parents also talked about other peoples' reactions to their child's disability from within their own communities ("Asians") that lacked understanding and were judgemental. The lack of understanding was related to people's limited exposure to individuals with disabilities:

Adeela: "...some people haven't got the understanding or they've never seen it so they don't understand it do they?"

As a result of a lack of prior knowledge about disabilities, some of the parents described older relatives holding unrealistic expectations of their children in terms of their capabilities. For example, Kulbir described her mother in-law's constant focus on her daughter's limitations:

Kulbir: "Grandma was the worst, she was so critical of my daughter, saying 'why doesn't she do this?'. She was getting annoyed with her all the time and getting angry... she knows there's something wrong but obviously her age and so forth, she was less understanding."

"There's a stigma attached to things like disability"

Associated with the lack of understanding was stigmatisation during social interactions with members of their own communities. For some parents, the word 'disabled' held very distinctive meanings. For example, Adeela described her belief that, in the Asian community, the word is loaded with negative connotations and refers to limited capabilities:

Adeela: "...If an Asian person says 'disabled', it offends me, they don't know what it means, they just use it to describe someone who can't do something, it's like when they used to use the word handicapped, it's like

a word that this person can't do nothing, that's how it comes across to me."

Additionally, some of the parents found that their bicultural identities made it difficult for them to conceptualise disability in a specific way. Sanjit described feeling caught between the conflicting and contradictory interpretations of disability arising from her Indian cultural values and her Western values:

Sanjit: "There's a stigma attached to things like disability in our Indian community you know, it's a bad thing. Indians can be very ashamed of it, like responses from family were, 'don't go around telling people that, you have to get her married at some point' that's the reaction I was getting and obviously being born here, you think more like a Westerner so it didn't bother me that she had a disability, but the Indian side of me was bothered [laughs]."

"They have their own beliefs"

Parents also described feeling pressurised by family members to seek out traditional Asian remedies as a cure:

Kabir: "My sister-in-law's family used to have a son, he couldn't walk. They took him to Pakistan for about six or seven months and he start walking. They give us examples like this and then they say 'oh you maybe should take her then.'"

When asked their thoughts about the use of traditional Asian healing practices, all the parents met the idea with initial scepticism. These practices included seeking advice from religious leaders or visiting holy sites in their country of heritage. They described how older relatives were likely to prescribe traditional healing practices and view Western medical approaches as more likely to be wrong.

Khalida: "I really do think white people think so much more positively, whereas Asians do think negatively; a lot of the time they tend to think that their own remedies will work whereas what professionals are saying 'oh that could be wrong.'"

Despite feeling pressurised to seek out traditional treatments, all the parents reported greater compliance with Western medical interventions, but remained open to traditional practices.

Master theme 3: Having to cope

This theme describes the adjustments the parents made in order to cope with their caregiving roles.

Coming to terms with life as a caregiver

Parents acknowledged that their caregiving responsibilities were something that they had “no choice” but to accept. Associated with this acceptance was the need to make personal sacrifices in order to meet the continuous demands of caregiving. For Khalida, caregiving left her feeling trapped and overwhelmed by a responsibility to perform, regardless of her own needs.

Khalida: “This is my life now, this is what I have to do even if I’m down I’ve gotta get up and feed ‘em and change ‘em and do everything that I would do on a normal day though I’m not up to it and on days like that you do realise how hard it is and that you’ve still gotta do it all alone.”

Adapting to a new culture

Non-British born parents described a two-fold struggle, firstly in adapting to their children’s disability and secondly, in adapting to a new culture. For example, in the extract below, Kulbir describes her struggle in trying to understand her daughter’s delays whilst at the same time trying to adjust to a new lifestyle:

Kulbir: “I was from India so I didn’t know what happened, I didn’t know myself, I was young when I came here, I didn’t know what the lifestyle is like here.”

These parents acknowledged that not being able to communicate in English was the biggest barrier to adapting to life in the UK. Having to access services and liaise with English speaking health professionals was a great motivator for the parents in English language acquisition:

Nazia: “When we had lots of visitors (health professionals), it helped me quite a lot to speak with them. I had to speak, otherwise there was nobody there to translate for me ...Two or three years I was very shy, it was just hesitation, I felt stuck and felt like my pronunciation was not good...”

when it's not your first language it's always different and it is very difficult."

Many of the parents felt they had no other option other than to learn to speak English themselves.

Discussion

The following discussion explores the three master themes detailed in the results section in relation to existing literature and in terms of their implications for service delivery.

Master theme 1: Living with loss, uncertainty and overwhelming responsibility

As expected, the experiences described by parents in this study are similar to those in studies examining the caregiving experiences of families from the white British culture caring for individuals with disabilities (e.g., Baker et al. 2003; Emerson 2003). Caregiving of a child with functional and cognitive impairments introduces new challenges often associated with greater dependency. For example, the first master theme described the psychological consequences of caregiving including anxiety about the future and vulnerability of the child, dealing with losses and struggling to cope with the numerous challenges that have been highlighted by previous research (e.g., Hastings and Beck 2004; Hastings 2003). As a result of facing numerous stressors, families with children with developmental disabilities have been shown to experience more long term and persistent stress and adverse mental health than those without a child with developmental disabilities (Baker et al. 2003; Emerson 2003). It is important to note that, while these more negative experiences are very common, they are by no means universal and many families will focus on the gains rather than the losses arising from having a disabled child (cf. Hastings & Taunt, 2002).

Some challenges were unique to the mothers in this study. For example, the mothers, not the fathers, reported experiencing a loss of their own lives. This may be because the fathers in this study shared their caregiving responsibilities with their wives, whereas the mothers tended to carry the bulk of the caregiving on their own. As well as the stress associated with caregiving the mothers in the current study also highlighted their struggle to manage their “*multiple roles*”, including being a caregiver to the child with intellectual/developmental disabilities, being a mother to other children, a wife and a daughter-in law. Research suggests that family caregivers, in particular mothers, often take on multifaceted responsibilities of long-term disability management (Eisenhower and Blacher 2006; Tehee et al. 2009).

Master theme 2: Learning about disability and facing stigma

Parents often seek interpretations of disability in relation to their own lives, which tend to be shaped by cultural resources (family and friends) and expectations of normative child development (Skinner & Weisner 2007), as was described in the sub theme “*everything was delayed*”. In the present study, this allowed parents to evaluate their own child’s progress and recognise the delays. Interestingly, the parents described getting a diagnosis and seeking medical help early on. This emphasis on early intervention and diagnosis is very distinct from other research in which South Asian parents often have low service uptake and receive later diagnoses of disabilities (Bywaters et al. 2003; Hatton et al. 2010). This may be influenced by the fact that the parents in the current study demonstrated higher levels of integration with British culture. Although there is no research exploring the effects of acculturation on service usage in British South Asian communities, research in the United States has demonstrated that acculturation in ethnic minority groups (mostly Latino groups) is linked to increased service uptake, especially in individuals who are able to speak English (Fassaert et al. 2009).

These results may also reflect the fact that some of the parents were recruited via NHS services and are therefore more likely to be better engaged with services.

Parents in the current study described having to make sense of their child's disability in relation to two cultures, as highlighted in the sub themes "*there's a stigma attached to things like disability*" and "*they have their own beliefs*". This involved constructing and negotiating their understandings of disability in relation to Western views of disability and a 'traditional' approach influenced by their Asian heritage. Asian cultures place far greater emphasis on collective needs, interdependency and conformity as opposed to the individuality promoted in Western values (Suzuki et al. 2001). According to Berry (2005), this can lead to acculturative stress, when individuals face problems as a result of intercultural contact. The current findings suggest that British South Asian caregivers are likely to be exposed to a different set of pressures which are culturally unique to them and may be a reflection of different rates of acculturation (Berry 2005).

Master theme 3: Having to cope

We know little about how South Asian parents in the UK cope with the stressors of caregiving. However, they may be more likely than White British parents to attribute their child's disability to external events (e.g., religious, supernatural or spiritual causes) ((Fatimilehin and Nadirshaw 1994; Katbamna et al. 2004; Bywaters et al. 2003). Such external attributions may increase acceptance and coping amongst families (Durà-Vilà and Hodes, 2009) although research exploring this is limited. In the current study the parents' narratives demonstrated a greater compliance with medical understandings of disability

which appeared to lead to, or be associated with, greater service usage. Despite the fact that they were accessing services, parents felt unable to manage the considerable challenges they faced on a daily basis. They used emotion-focused strategies such as “*get on with*”, which are likely to provide temporary relief but do not change the nature of the caregiving burden or make it more manageable.

Parents born outside of the UK talked about coping both with respect to their caregiving roles and the process of adapting to a new culture. Navigating complex NHS service systems is a difficult task, made harder for immigrants who often have to deal with issues surrounding residential status, eligibility for NHS treatments and language barriers (Sue and Sue 1999). The parents described having to quickly adjust to a British lifestyle and emphasised the importance of learning to speak English using a trial and error method which involved regularly liaising with services and thereby learning through lived experience. Cultural competence and sensitivity amongst service providers is vital in allowing this to happen. This sub-theme provided a unique insight into the adaptation of immigrant parents and suggests that they employed an acculturation strategy of “integration” (Berry, 1997). It also highlights the importance of language in accessing services as has been demonstrated by other research (Bywaters et al., 2003; Hatton et al., 2010).

Concluding comments

Overall, the findings suggest that this group of South Asians adopted Western perspectives while trying to incorporate traditional Asian cultural beliefs. This sometimes led to conflict and confusion. It was also apparent that parents struggled to cope with the competing challenges of caregiving and managing everyday life stressors.

It is important to note the limitations of the study. Firstly, it used a small sample with a focus on the families of disabled children rather than adults and all of whom came from a specific geographical area. The main focus of IPA is to provide detailed accounts of the experiences of a small number of participants rather than try to make generalizations about whole populations. As a result, the experiences described are not necessarily generalizable to other South Asian families. The study used demographic variables as measures of acculturation. While useful, these failed to account for individual differences and other factors which may have affected the way in which South Asian parents adapted to a new culture. Although the study attempts to make distinctions between the experiences of mothers and fathers this was difficult due to the small sample size and more general nature of the overarching research question. Therefore, it may be important for future studies to explore these differences in more depth.

Lazarus *et al.* (1984) suggest that, during stressful events, promoting positive emotions over negative ones can reduce adverse psychological consequences and support continued coping through the replenishment of resources that may have been depleted by stress. The same authors suggest that strategies such as gathering information and resources to help deal with problems, decision making and conflict resolution can help individuals deal with stressful situations in more positive ways. Parents in the current study reported feelings of uncertainty about their children's future and vulnerability which psychoeducation may help to alleviate.

Other helpful interventions might include parent support groups whereby parents with positive perceptions can help parents in the early stages of adjustment to develop positive but realistic expectations. This would also provide an opportunity to hear about successful transitional journeys of individuals with developmental disabilities into adulthood which may

help families be more hopeful about their own children's futures. Support group settings may also provide a safe forum where parents can discuss their issues around fears about the future and care-giving difficulties without being judged. Some of the parents in the current study were recruited from a carers support group and stated that they found it helpful to obtain information about benefits and health and social care services from other families caring for disabled children. South Asian cultures have been shown to promote obligations and responsibilities to caregive within the family (Katbamna et al., 2004) and the mothers in this study described having to adopt an "*Indian mentality*" to get on with care-giving despite the challenges. Therefore, they may feel guilty about finding it difficult or challenging and may find it hard to talk to family members. A support group could allow them to reflect on these issues without such concerns.

The study suggests a number of recommendations for the way in which services are provided:

- Culture should be viewed as fluid and open to change rather than a set of beliefs and behaviours that are passed down from generation to generation. Service providers should, therefore, explore cultural and religious beliefs, age, time in country, languages spoken etc. in order to avoid providing care based on stereotypes.
- Extended families can be a source of support for parents as well as a source of anxiety due to stigmatising attitudes and alternative views about treatments. Consequently, it is important to explore complex family relations when working with families.
- Sharing information about the onset, causes and possible future implications of their children's difficulties may allow parents to better adjust to and plan for the different stages of their child's lives. This may help reduce feelings of uncertainty and help with decision making about interventions.

- Service providers should be sensitive to the possibility that parents may hold alternative views about interventions and treatment options. These may require exploration with families in terms of how they fit with more biopsychosocial ways of working.
- Families for whom English is not their first language may require extra support and information when navigating complex service systems.
- Services should be family-centred, responding to the individual circumstances of families and offering support in culturally sensitive ways.

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Table 1: Participant details

Pseudonym	Age	Relationship to disabled child	No. of children	Country of birth	Time since immigration	Religion	Languages written and spoken	Education	PARTNER DETAILS	
									Country of birth	Languages spoken
Khalida	27	Mother	3	England	n/a	Muslim	English and Urdu	GCSEs	Pakistan	Urdu
Fahmeeda	28	Mother	4	England	n/a	Muslim	English, Urdu and Mirpuri	GCSEs	Pakistan	Urdu and Mirpuri
Nazia	30	Mother	3	Pakistan	10 years	Muslim	English, Urdu and Punjabi	ESOL, UK	England	English and Punjabi
Kulbir	36	Mother	3	India	18 years	Sikh	English and Punjabi	GSCEs, UK	England	English and Punjabi
Asim	38	Father	3	Pakistan	15 years	Muslim	English and Urdu	ESOL, UK	Pakistan	Urdu
Sanjit	38	Mother	3	England	n/a	Sikh	English and Punjabi	Pre-vocational course	India	English and Punjabi
Kabir	42	Father	2	Pakistan	20 years	Muslim	English and Urdu	O levels, UK	Pakistan	Urdu

Table 2: Master and sub themes reflecting participants’ experiences of caring for children with intellectual/developmental disabilities and the number of participants who represent each theme

Master theme	Sub theme	Number of participants representing each theme
Living with loss, uncertainty and overwhelming responsibility	<i>An uncertain future</i>	7
	<i>Concurrent losses</i>	6
	<i>Fears about vulnerability of child</i>	5
	<i>Managing multiple responsibilities</i>	7
Learning about disability and facing stigma	<i>“Everything was delayed”</i>	6
	<i>Struggling to understand the diagnosis</i>	5
	<i>“They just don’t understand it”</i>	5
	<i>“There’s a stigma attached to things like disability”</i>	6
	<i>“They have their own beliefs”</i>	5
Having to cope	<i>Coming to terms with life as a caregiver</i>	5
	<i>Adapting to a new culture</i>	4